RW has undertaken paid consultancy for, received hospitality and travel funds from, and undertaken research for GlaxoSmithKline and Pharmacia, of smoking cessation products.

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Withdrawal of life sustaining treatment

Patients' autonomy and values conflict with the responsibilities of clinicians

Ms B, as she was called in court and in the media, was a 43 year old professional woman who in 1999 had a haemorrhage in a cavernous haemangioma in her upper spinal cord. After an almost complete recovery she had a re-bleed in February 2001, which rendered her quadriplegic and dependent on artificial ventilation. Specialists who reviewed her all agreed that she had a negligible chance of substantial recovery, and she was advised to consider specialist rehabilitation. Ms B went to great lengths to gather information about her prognosis. She remained adamant that living on a ventilator would be intolerable to her because of the level of dependence on others and the lack of control over her own body she would have, and she requested to have her ventilation discontinued. The clinicians treating her felt unable to carry out her wishes, and Ms B eventually took to court the NHS Trust treating her.

Dame Elizabeth Butler-Sloss judged that Ms B was indeed competent to decide on her treatment, and therefore her decisions about her treatment, whatever they were, must be respected.[1] The judgment reviewed precedents for this, including the judge's own previous statement that "a mentally competent patient has an absolute right to refuse to consent to treatment for any reason, rational or irrational, or for no reason at all, even where that decision may lead to his or her own death." The same principle was contained in a 1999 BMA report and is included in guidelines currently being drafted by the General Medical Council.[2 3] The judgment also emphasised that "the right of the competent patient to request cessation of treatment must prevail over the natural desire of the medical and nursing professions to try to keep her alive."

When a patient makes a decision, especially one with serious consequences, which so clearly goes against professional advice, this alone might lead a clinician to doubt his or her competence. However, this view of clinicians is clearly tautological and goes against the legal principle above. Competence must be established instead on the basis that the patient is capable of assimilating and understanding information about her condition, appreciates the personal relevance of this information, is capable of discussing it with others, and is able to form judgments by weighing up the information she has acquired.

In this case, it was clear that the patient had based her decision predominantly on her values—personally determined weights assigned to one course of action relative to others. In essence, she valued the continuing life she faced, particularly being dependent on others, as worse than death. Doctors must recognise the differences between values and knowledge. Patients' values have tended to be neglected in considerations of their competence.[4] A patient's values cannot be accommodated by insisting on offering the individual more facts to assimilate, but by acknowledging and trying to understand the person's experience of illness and treatment.[5] Values can, and often do, alter with changing circumstances and experience.[6] What matter here are the individual's values at the time the decision needs to be made. It was argued that Ms B could not reach a valid decision about rehabilitation until she had experienced it.[7] However, it is clearly illogical to assert that valid consent is only possible in retrospect.

Instances were cited, both in court and in the media, where individuals faced with the same decision as Ms B opted for rehabilitation, and later said that they were pleased to have done so. Unlike Ms B, these people must have given consent to continuing ventilation, and were therefore at the very least ambivalent, or had reserved judgment, about the anticipated quality of their lives after rehabilitation. To extrapolate from such anecdotes to Ms B's circumstances would be invalid. Had she opted to start rehabilitation, Ms B might over time have changed her values. However, testing whether this might happen would be illegal as well as unethical. With acceptance of patients' autonomy comes the inevitable uncertainty whether the patient might have changed her view later.

Managing such situations can be very distressing for many clinicians, who see their work focused on the preservation of life. There will be other instances, as here, where clinicians feel unable personally to carry out a patient's request to withdraw from life sustaining treatment.[8] Where this occurs, the present judgment indicates that clinicians have a duty to find someone else to carry out the patient's wishes.[1] In the first instance, it may often be helpful to seek independent assistance and advice from appropriate medical experts, to clarify the differences in the views of patient and clinicians, and to help in devising a management

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plan. This consultation process should involve the patient as fully as possible. It is only after such steps have failed that an application to the high court should be considered. In England and Wales, the official solicitor is available to offer advice at any stage.

Decisions to withdraw treatment are not uncommon in some clinical settings. In palliative care, they are the norm. They are commonly reached by mutual agreement between the patient and clinicians, and treatment focuses on managing the process of dying, rather than sustaining life. The increasing use of technologies capable of sustaining life means that such decisions are likely to become more common, but also more complex.[9] When a patient chooses to withdraw from life sustaining treatment, helping that person achieve a "good" death is a legitimate goal for healthcare professionals.[9] From the patient's perspective, key considerations are adequate pain and symptom management, avoiding inappropriate prolongation of dying, achieving a sense of control, relieving burden, and strengthening relationships with loved ones.[10]

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TS was instructed as an independent expert in this case by the official solicitor, and made personal assessments of Ms B, as well as studying Ms B's medical records and other background information. He had her permission to write up the case.
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The world's most neglected diseases

Ignored by the pharmaceutical industry and by public-private partnerships

Infectious diseases can be considered "neglected" when there is a lack of effective, affordable, or easy to use drug treatments. As most patients with such diseases live in developing countries and are too poor to pay for drugs, the pharmaceutical industry has traditionally ignored these diseases. Over the past decade, however, the public sector, by creating favourable marketing conditions, has persuaded industry to enter into public-private partnerships to tackle neglected diseases such as malaria, HIV, and tuberculosis. Yet some infectious diseases—the world's "most neglected" diseases—are still being ignored not just by the pharmaceutical industry but also by public-private partnerships.

Why have these partnerships ignored the most neglected diseases, such as kala-azar, Chagas' disease, and sleeping sickness? This question was explored at a recent meeting in New York, organised by Médecins sans Frontières.[1] The answer lies in the social contract that exists between the public and private sectors.

The public sector has decided to make it public policy to leave drug development in the hands of the pharmaceutical industry. This industry in turn invests almost exclusively in developing drugs that are likely to be marketable and profitable—drugs for conditions such as pain, cancer, heart disease, and baldness. Public policies, such as tax incentives and patent protection, are geared towards this market driven private investment. As a result, out of 1393 new drugs marketed between 1975 and 1999, only 16 were for neglected diseases,[2] yet these diseases accounted for over 10% of the global disease burden. In contrast, over two thirds of new drugs were "me too drugs" (modified versions of existing drugs), which do little or nothing to change the disease burden.

The pharmaceutical industry only enters into public-private partnerships when it sees at least some potential market for its drug. For example, although people with malaria in the world's poorest countries cannot afford to pay for new malaria drugs, Western travellers can. Similarly, patients with tuberculosis or HIV in Africa or India cannot afford to purchase new treatments. However, many patients in the United States or Europe, whose health expenditure is covered partly by government run health insurance programmes, can pay for these treatments.

When the pharmaceutical industry sees enough of a market, the public sector then has sufficient leverage, or bargaining power, to persuade the private sector into a partnership. The bargaining power involves creating favourable conditions that make it attractive for industry to invest in drug development. For example, the public sector might reduce the costs of research and development through grants, tax credits, or public support for clinical trials, or it might create a purchase fund, in which donors ensure that there is a pot of gold ready to buy the new drug once it is developed. Examples of this type of approach are the Medicines for Malaria Venture, the International AIDS Vaccine Initiative, and the Global Alliance for TB Drugs Development.

When it comes to the world's most neglected diseases, however, these present absolutely no market opportunities. Without such opportunites, there is no incentive for the pharmaceutical industry to invest in

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